

A GUIDE TO CLM DATA COLLECTION METHODS

ATAC, 2023



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Abbreviations and Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ATAC	Alliance Technical Assistance Centre
ATS	Amphetamine Type Stimulants
CI9RM	The Global Fund's COVID-19 Response Mechanism
CBO	Community-based organisation
CCM	Country Coordination Mechanism
CLM	Community-Led Monitoring
CLO	Community-led organisation
CSO(NGO)	Civil society organization or non-governmental organisation is any non-profit, voluntary citizens' group which is organized on a local, national or international level.
EDM	Electronic Dance Music
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HTS	HIV Testing Services
IBBS	Integrated Bio-Behavioural Surveillance
IEC	Information, Education and Communication
ITPC	International Treatment Preparedness Coalition
KP	Key Populations
LGBTIQ+	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer/Questioning, Asexual and other sexually or gender diverse people or people with nonheteronormative / nonbinary sexual and/or gender identities
MSM	Men who have sex with men
NGO	Non-Governmental Organisation
NSP	Needle and Syringe Programs
OAT	Opioid Agonist Treatment
OCF	Optimized Case Finding
OST	Opioid Substitution Therapy
PAS	Psychoactive Substances
PEP	Post Exposure Prophylaxis
PEPFAR	The United States President's Emergency Plan for AIDS Relief
PLHIV	People Living with HIV
PrEP	Pre-Exposure Prophylaxis
PMTCT	Prevention of Mother-To-Child Transmission of HIV

Abbreviations and Acronyms

PWID	People Who Inject Drugs
PWUD	People who Use Drugs
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
SUD	Substance Use Disorder
SW	Sex Worker
TB	Tuberculosis
UIC	Unique Identification Code
WHO	World Health Organisation

Rationale

The goal of community-led monitoring (CLM) is to improve access, quality and outcomes of health services. CLM implementers can suggest program and service delivery improvements based on the analysis of the current situation (gaps, what works, what doesn't, what services are available and what services are missing, how easily accessible they are, etc.). Such analysis requires reliable data; thus, data collection is the basis of all CLM activities and, ultimately, of the improvements of services and the response in general.

When the COVID-19 pandemic hit, the restrictions that followed presented challenges for service delivery itself and for CLM implementation, too. Key and vulnerable populations, like homeless people, sex workers, LGBTQI individuals, people who use drugs, ethnic minorities, and prisoners, were particularly impacted. Access to testing, face-to-face consultations and other services that require physical presence in a facility has significantly decreased. Despite the challenges, civil society organizations (CSOs) and community-based organizations (CBOs) have adapted by bringing about changes in service delivery modalities, such as offering online consultations, self-testing, and home delivery of medications and other commodities.

As we continue to address the ongoing impact of COVID-19, as well as prepare ourselves for potential future outbreaks, pandemics or emergency situations, it is crucial to ensure that CLM efforts are planned with consideration for these recently experienced realities. This guide will focus primarily on online, digital, and remote data collection methods, which are highly relevant in such contexts.

Purpose of the guide

The purpose of this guide is to support representatives and members of CSOs, CBOs, community-led organizations (CLOs), activist groups, and other relevant stakeholders globally who intend to engage in or are already implementing community-led monitoring interventions within disease-specific programs. It offers practical advice and an overview of data collection as a crucial step in the CLM cycle.

This resource is also valuable for TA providers, governmental institutions, donors, and technical agencies supporting CLM, helping them understand the processes involved in CLM data collection and plan their programs and support accordingly.

The guide is not exhaustive but serves as a starting point, divided into sections that cover different types of data collection methods, including both quantitative and qualitative approaches, providing useful tips and examples for community-based and -led groups and organizations. Additionally, it describes how to collect and use data when restrictions related to epidemic/pandemic/emergency outbreaks limit access to available and potential data sources, aiming to provide communities with ways to design, implement, and carry out CLM on the availability, accessibility, acceptability, and quality of health programs and services.

Target audience / who should use this guide

This guide is designed for members, groups, and organizations of key and vulnerable and other affected populations working at local and/or national level that are planning to engage in community-led monitoring of HIV, TB, malaria, and COVID-19 prevention, care and treatment services.

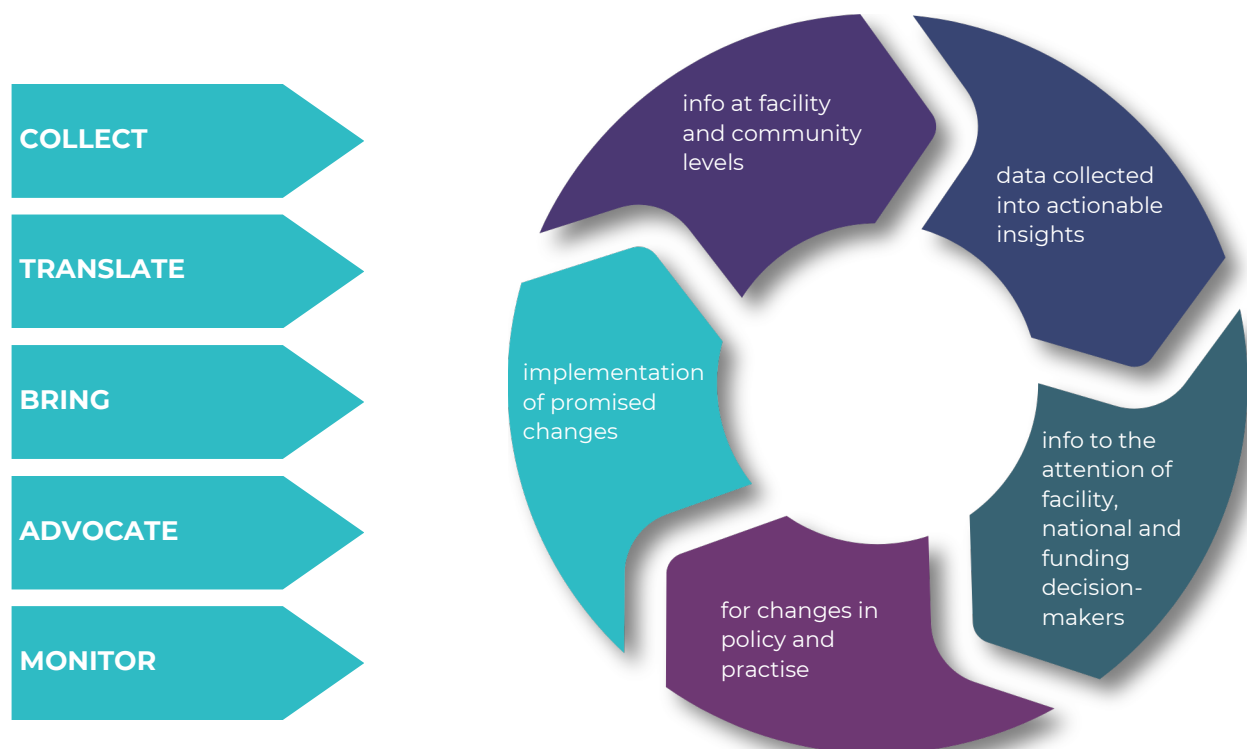
How to use this guide

This document is intended as a reference guide on CLM data collection. Users of this guide can select specific sections of interest or use it holistically to gain an overall understanding of the types and stages of data collection methods and choose the most appropriate combination for their CLM objectives. This guide gives an overview of the most frequently used methods that have proven helpful for CLM data collection, specifically done remotely or online.

Planning for data collection activities in CLM

Community-led monitoring includes many different components, methods, and approaches, but in general, it can be defined as a practice that combines systematic and routine data collection by communities and using that data for evidence-based advocacy to improve accountability, governance, and quality of HIV, TB, malaria, COVID-19, and other health services.

Key CLM Processes



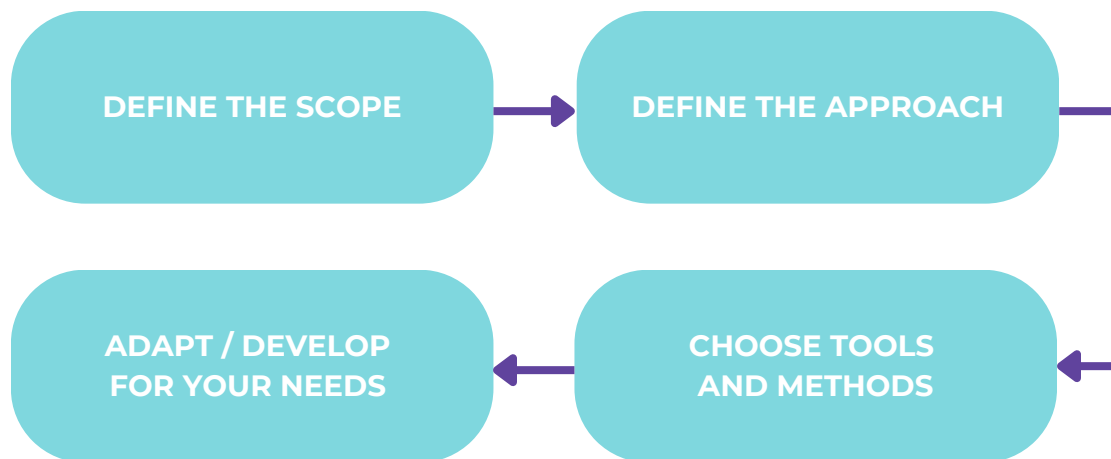
Understanding key CLM processes is helpful for CLM planning and preparing the required resources and for effective implementation and utilization of collected data for advocacy.

Collection of data is one of the first steps in any CLM activity after preparation (problem identification, selection of indicators and methods, etc.) and planning and is the basis for any further CLM-related action. It is important that people involved in the collection of data have the necessary knowledge and skills regarding various data collection methods and approaches while ideally also being members of the key affected community. In practice, it does not often happen this way. The data published in the “Best Practices for Community-Led Monitoring” by the Community-Led Accountability Working Group (CLAW) shows that the focus of the monitoring is usually determined by the organization(s) implementing the project (in 69% of programs) and community members (62%), although a minority of respondents described donor and government influence in designing data collection tools (26% and 23%, respectively).

Depending on the components and indicators that are intended to be monitored, the CBO/CLO/community representatives who are planning to carry out CLM will determine the methods and activities to be used in the process and, correspondingly, the approach to data collection as such.

Step-by-step CLM planning process

Before starting your key CLM activities, you need to plan your CLM, define its scope and approach, choose tools and methods, and adapt them for your needs, as shown in the graphics below:



1. Defining the scope – the area that needs to be monitored will be based on the focus areas of the organization/group that is implementing CLM. When planning an overall CLM strategy for the organization or program, you would be looking at the wider picture of what you do and what you need to include. When planning a particular CLM activity, you will be narrowing down to a particular topic, service, or activity and focusing on that in the further steps of planning.

The data published in the “Best Practices for Community-Led Monitoring” by the Community-Led Accountability Working Group (CLAW)¹ shows that the most common topics monitored include accessibility and quality of services for key and vulnerable populations (90% of programs); stigma, discrimination, and staff attitudes (82%); availability of services in the community (79%); and availability of medicines and stock-outs/shortages (79%).

¹ Community-Led Accountability Working Group (CLAW). 2022. Best Practices for Community-Led Monitoring. Available at: <https://healthgap.org/wp-content/uploads/2022/09/CLAW-Best-Practices-in-Community-Led-Monitoring-EN.pdf>

EXAMPLES

Below (and in the annexes section), you can find some examples of categorization and corresponding topics as to what you may want to include in your CLM plans.

The following below is an example of COVID-19-specific indicators that became relevant in the time of the restrictions it brought about.

It is important to note that not just the method of monitoring should be revised at the time of any restrictions or emergency situations, but also the areas you are looking at should be carefully revised/adapted, or specific emphasis or angle should be used when looking at the standard scope.

INDICATOR	WHY IT IS RELEVANT IN THE CONTEXT OF COVID-19?
QUANTITATIVE	
Number of people living with HIV receiving multi-month ART dispensing	Countries are rapidly scaling up multi-month dispensing to decongest health facilities during COVID-19. Yet, evidence from UNAIDS suggests that the supply of medicines dispensed does not always match the policy, often due to stock unpredictability, which has been exacerbated by COVID-19.
Number of TB tests conducted using rapid molecular platforms	GeneXpert machines are being repurposed to test for COVID-19. As a result, rapid molecular TB testing rates have reportedly plummeted in many countries. In South Africa, for example, using this machines for COVID -19 testing resulted in a 48% decline in GeneXpert TB testing, which led to a 33% decline in the number of people diagnosed with TB and a significant decrease in TB case notifications.
Number of people living with HIV on ART who are lost to follow up	PEPFAR data show a 1.5% decline in treatment retention in South Africa - about 100,000 individuals lost from care - between 27 March and 5 June (during the Level 4-5 lockdown).
QUALITATIVE	
What are the challenges that people living with HIV face in adhering to ART now?	Food insecurity, mental health and suspension of support groups for people living with HIV have all been reported since COVID-19 began. These issues are likely to affect the ability of people living with HIV to adhere their medication.
How do legal restrictions on movement affect access to food, health, care, shelter or other basic needs?	The Ugandan Medical Association reports that there have been delays in receiving travel permits during lockdown and that, in the interim, doctors who drive without them have been beaten arrested and tortured.

Another resource that includes some possible monitoring questions for a given topic/indicator/aim of CLM is EHRA’s web tool designed for choosing CLM tools that best match your needs².

2. Defining the approach – at this stage, you are forming a plan for your CLM activity. You should come up with the goals and objectives of the activity, define the key principles guiding the process, formulate some hypotheses on the issues that you will be looking at, and define the geographical scope, focus, and sample for the CLM activity.

3. Choosing tools and methods will depend on the topic and approach, as some specific data collection methods are better suited for collecting particular types of data.

What I need to monitor	What’s the best method to use
<ul style="list-style-type: none"> • whether and to what extent stigma has made it difficult for people to access services • the proportion of people who have been denied access to prevention and testing/screening • the number of people who have discontinued (e.g., antiretroviral therapy (ART) for HIV) • the number of people who reported not starting treatment and the reasons for this 	<ul style="list-style-type: none"> • analysis of the data collected from existing CLM platforms (e.g., software solutions such as REAct and OneImpact) • survey questionnaire • focus groups
<ul style="list-style-type: none"> • do prevention commodities correspond to the current drug scene and/or risk practices and the specific needs of particular groups within KPs 	<ul style="list-style-type: none"> • analysis of distribution records/statistics from service providers • survey questionnaires (including needs assessment component)
<ul style="list-style-type: none"> • what barriers prevent people from starting and continuing to use PrEP? 	<ul style="list-style-type: none"> • semi-structured interviews for identifying the barriers • survey questionnaires for estimating how common the barriers are
<ul style="list-style-type: none"> • are the information materials of suitable quality? 	<ul style="list-style-type: none"> • content analysis (secondary data analysis) of materials accessible and handed out to communities • surveys and interviews asking recipients of care if they find the information materials useful

²Eurasian Harm Reduction Association (EHRA). CLM Tool. Available at: <https://harmreductioneurasia.org/clm-tool>

<ul style="list-style-type: none"> • is the actual service implementation compliant with the standards and procedures put in place? 	<ul style="list-style-type: none"> • desk review (secondary data analysis) of the procedures and standards • desk review (secondary data analysis) of patient records³ • observations • surveys/questionnaires
<ul style="list-style-type: none"> • are the provided services gender sensitive? (e.g., are childcare needs taken into account, attitude, understanding of peculiar needs) 	<ul style="list-style-type: none"> • service provider evaluation (analysis of personnel training curriculum, policies and procedures, including policies for PSEAH)⁴ • survey questionnaires
<ul style="list-style-type: none"> • does the menu of provided services include specific tailored services for particular groups of key populations (e.g., transgender people, MSM who practise chemsex⁵, prisoners, homeless people) 	<ul style="list-style-type: none"> • survey questionnaires with the management and individual providers from service provider organizations • surveys/questionnaires for the clients

According to the data presented in “Best Practices for Community-Led Monitoring” by the Community-Led Accountability Working Group (CLAW)⁶, in 55% of programs surveyed, data are collected by members of communities impacted by the three diseases using electronic tools such as District Health Information Software 2 (DHIS-2), CommCare, and OneImpact. These are digital platforms designed specifically for CLM or for other health-related purposes, but including CLM. Some of them will be explained later in this guide.

4. The scale of the **adaptation or tailoring of each tool/method** depends on the nature of what you're monitoring. For typical activities/services, existing tools may suffice. However, for unique projects or in countries with little CLM experience, you might need to tailor existing tools or create new ones from scratch to address specific situations. It would be a rare occasion that you would not find something that can be adapted for your needs amongst the existing tools and would need to develop your own from scratch.

³Patient records and procedures and standards for secondary data analysis may not always be easily accessible to a CLM implementer who is external from the monitored health facility.

⁴Personnel training curriculum, policies and procedures may be difficult to access for an external CLM implementer.

⁵Chemsex is intentional sex under the influence of psychoactive drugs, mostly among men who have sex with men. It refers particularly to the use of drugs such as mephedrone, GHB, GBL, and methamphetamine before or during planned sexual activity. These drugs are often used in combination to facilitate sexual sessions lasting several hours or days with multiple sexual partners

⁶Community-Led Accountability Working Group (CLAW). 2022. Best Practices for Community-Led Monitoring.

Available at:

<https://healthgap.org/wp-content/uploads/2022/09/CLAW-Best-Practices-in-Community-Led-Monitoring-EN.pdf>

Methods of data collection used for CLM

There are two types of data that will need to be collected within CLM: quantitative and qualitative data.

WHAT'S THE DIFFERENCE BETWEEN QUANTITATIVE AND QUALITATIVE DATA?

Quantitative Data

- Countable or measurable, relating to numbers.
- Tells us how many, how much, or how often.
- Fixed and universal, “factual”.
- Gathered by measuring and counting things.
- Analyzed using statistical analysis.

Qualitative Data

- Descriptive, relating to words and language.
- Describes certain attributes, and helps us to understand the “why” or “how” behind certain behaviours.
- Dynamic and subjective, open to interpretation.
- Gathered through observations and interviews
- Analyzed by grouping the data into meaningful themes or categories.

Quantitative Data

If the indicator that you are planning to monitor focuses on the number of people who are accessing a service or quantifies the duration of a procedure, quantitative indicators are needed.

Quantitative questions allow you to specify the extent and duration of the issue:

- How many people were impacted (e.g., how many people had not been able to come to their OST site)?
- How many people have been reached (e.g., with HIV testing)?
- How long was the service suspended (e.g., how long was the tuberculosis dispenser closed for or was lacking a particular medication or other required health products in stock)?
- How many facilities in the area provide the service (e.g., how many clinics provide PrEP/HIV testing, tuberculosis screening in city X, what is the coverage for a particular facility, etc.)?

Quantitative data can, for example, be used to identify the prevalence of an issue that comes up during quantitative data collection. This means that when you are collecting numerical data, you can use that data to determine how often a particular issue occurs within a specific population. For example, if a survey is designed to collect quantitative data on a health issue, the prevalence can be determined by analysing the frequency or percentage of individuals having certain characteristics related to that health issue. This quantitative approach provides a clear (and measurable) understanding of how widespread a particular issue is within the specific population.

Qualitative Data

If your monitoring question focuses on describing the extent and nature of an issue by detailing who is affected and the impact of the experience on individuals or communities, qualitative data is needed. Qualitative data allows you to describe the “what” and “why” of the issue. It is especially powerful for gaining insight into underlying barriers or facilitators for the Availability, Accessibility, Acceptability, Affordability, Appropriateness, and Quality of services. It is based on descriptive accounts, observations, and perceptions that can illustrate how people think or feel, typically gathered from interviews, focus groups, and photovoice.

Qualitative data is used to further explain or provide a more in-depth explanation of quantitative data, so it is often collected as a follow-up of quantitative data collection.

Qualitative data helps you to answer:

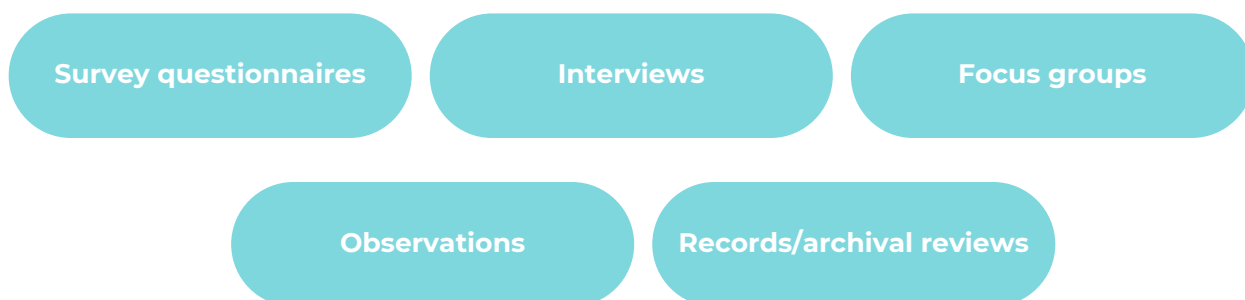
- What underlying issues are driving the challenges? (e.g., if a particular clinic is closed for two weeks, why is it closed? Is it in quarantine?)
- Why do you experience the identified challenges? (e.g., is there a staff shortage? is there funding shortage to ensure relevant protection measures, inappropriate attitude of providers/stigma/unethical behavior, distance to the facility, etc.)
- What is the impact of this issue on community members? (e.g., how does skipping medication on a daily PrEP regimen/OST program influence the client’s prevention/treatment success)

Quantitative data has its strengths, including objectivity, as it provides a clear numerical representation of trends, which makes it less prone to interpretation bias. If you collect quantitative data, you can use larger sample sizes, which makes it easier to generalize findings to a broader population. However, there are drawbacks, such as the potential lack of depth compared to qualitative data, which can result in missing important information about participants’ experiences. On the other hand, qualitative data provides rich, in-depth insights into participants' experiences.

The flexibility of qualitative approaches means you can explore unexpected themes that may emerge during data collection. However, qualitative data is subjective and can introduce bias. Qualitative data collection and analysis can also be time-consuming and resource-intensive.

Correspondingly, there are different methods for collecting both types of data.

Key methods for data collection that are used in CLM and that will be focused on in this guide are:



Additionally, CLM often requires formulating and submitting information/data requests to relevant institutions (e.g., Ministry of Health, AIDS Centres, relevant clinics, law enforcement/social protection/human rights protection agencies, NGOs, and other service providers), which will be explained in the secondary data collection section.

Here is an example/template of such request:

Cover letter for the official institution to request the data

Dear Dr./Ms./Mr. (Name of Recipient and Title if Applicable)

This letter is in regards to (Reason for Requesting Data). I am (Name of Person Requesting Data), and currently work in the (Name of Organisation). I am in charge of research and community-led monitoring, and am formally requesting permission to access (Type of Data). We are currently collecting data for (Reason for Data), and were given your name from (How the person was identified).

We intend to use the data collected, to assist in creating a (Reason for Data), and will be sharing it with (Name of person or organisation), in accordance with your organisation's protocols.

On behalf of myself and my team, we heartily express our gratitude in examining our request for data. We assure you that all protocols will be followed, and privacy regulations adhered to. If you have any questions or concerns, my contact information is (Contact information).

Best regards

(Signed name)

(Printed name)

Carrying out data collection in normal circumstances is oftentimes done in in-person interactions such as survey questionnaires, interviews, and focus groups. Since this guide focuses on carrying out data collection in times of restricted movement and face-to-face communication, the guide will focus specifically on online or remote data collection methods.

Considerations for online quantitative data collection

When dealing with quantitative data, you can:

- Gather the data via survey questionnaires or
- Use pre-existing data collected by others.

The main characteristics of working with quantitative data are:

- The data is collected by structured tools or instruments
- The results are based on larger samples that represent the population
- The data collection and analysis design can be replicated or repeated
- The person responsible for the data collection and analysis already has a clear idea and definition of the question(s) that he/she intends to answer

Steps to prepare for and carry out CLM involving quantitative data

Stage	What you should do
Stage 1: Getting Started	Begin by making assumptions about what you want to monitor in your community, additionally considering the impact of any existing restrictions (COVID-19/other pandemics or emergency situations) on, e.g., PWIDs attending regular appointments, if any.
Stage 2: Planning	Choose the best approach to answer your questions and design the CLM process.
Stage 3: Clear Definitions	Clearly define what you're investigating by turning your ideas into simple measurements. This makes collecting data easy and accessible.

Stage 4: Selecting CLM Sites and the Target Participants	Identify the most suitable location for gathering data, with online methods preferred during any existing restrictions (COVID-19/other pandemics or emergency situations), as well as when planning to reach participants in hard-to-reach and distant areas. Decide who will be part of your CLM (e.g., who will be the respondents of the questionnaires) based on your questions.
Stage 5: Collecting Data	Carefully plan and carry out the data collection process ⁷ .
Stage 6: Organizing Data⁸	Transform the information you collected into usable data.
Stage 7: Understanding Data	Analyze the data to find connections and patterns.
Stage 8: Making Sense of Data	Interpret the results and consider what they mean for your community.
Stage 9: Putting Data to Use	Use the findings to advocate for improvements and make positive changes in the services that you focused on in your CLM efforts.

Considerations for online qualitative data collection

Qualitative interviews are particularly useful when:

- You are exploring a new issue and would like key informants to give you a sense of the main factors that are impacting them.
- The issue is layered and complex, and it cannot be fully understood from a quantitative data source (or you would like to understand the context driving the quantitative data you are seeing).
- You want to gain an in-depth understanding of the experiences and needs of communities.
- You want to uncover the reasons why issues have happened (such as stock-outs or treatment interruptions) by discussing the experience with the respondents.

⁷More on this aspect is shared later in this guide.

⁸Once the data is collected, stages 6–9 become relevant. ATAC is developing resources on data analysis and communications, partnerships, and advocacy to further support CLM implementers, which can be useful to turn to regarding the next steps of working with the collected data.

Key considerations for CLM implementers when planning and conducting data collection for CLM qualitative data:

Ensuring Methodological Quality and Thoroughness:

- Assess if the virtual/online format is appropriate for your purpose and the questions you are posing.
- Consider any potential loss or gain from using virtual/online data collection methods.
- Address technological considerations, including appropriate tools, assistance, and participant barriers.
- Plan the recruitment of participants with varying levels of technological proficiency.

Ethics and Equity:

- Obtain informed consent through two-way communication with participants.
- Mitigate risks to participants' anonymity, confidentiality, and data privacy in the virtual/online format.
- Adapt timelines and plans to accommodate the virtual/online approach, if necessary.

For more practical information on planning online surveys, refer to the chapter "**Online Surveys.**"

***TIP/NOTE:** Before collecting any CLM data, an informed consent form must be presented to participants and expressed in a manner that is widely and easily understood. Consent forms must be kept separate from interview data and kept well-organized for easy reference. An example of such a form can be found in the annexes section of this guide.

Online data collection methods

Online surveys

Survey is one of the most commonly used methods to collect data for studies and community assessments and is a very useful method for CLM. Surveys use questions developed on a specific topic or theme and aim to collect the same information from all respondents. They are used to collect information about gender, sexual orientation, health, well-being, economic, and demographic aspects, as well as access to HIV, TB, malaria, COVID-19, or other health services.

Surveys are conducted through online platforms, email, telephone, or face-to-face interviews. However, during the COVID-19 pandemic, online platforms became the preferred data collection source for safety reasons. It eliminates any personal contact and the risk of infection. This is a good approach to use at times of any movement restrictions (COVID-19/other pandemics or emergency situations). Additionally, some participants feel more secure when they do not have direct contact with a data collector, and it may simply be more convenient and help cover a wider range of participants since it does not require any physical travel.

Advantages and disadvantages

Pros	Cons
Can be conducted among a very large number of participants	Answers may be dishonest
Relatively cost-effective	Participants may lose their interest midway
Easy to visualize and analyze, ensures fewer steps between data input and analysis	Questions might be left unanswered
Data is better protected	Questions could be unclear for participants
Surveys can cover a lot of different topics	Requires access to a device and internet
Implementers can access data from anywhere	

Steps for preparing and conducting online surveys for CLM

What you should do	How you should do it
1. Define your CLM focus	Determine the specific aspects of HIV, TB, malaria or COVID-19 service provision/response that you want to monitor within your community, such as treatment access, awareness levels, or prevention measures.
2. Decide on survey participants	At this stage, you determine who the participants in the survey will be. For an online survey, you might target a broader audience, reaching out to individuals connected to the topics of HIV, TB, malaria, and COVID-19 through virtual channels. This could include online communities, forums, or social media groups. For in-person surveys, consider involving community members directly affected by these health issues or those playing crucial roles in healthcare, support services, or advocacy within local settings.
3. Make it measurable	Transform your CLM goals into concrete and measurable indicators. For example, track the number of people accessing testing centers, the percentage of treatment adherence, or the availability of mosquito nets.
4. Create the online survey	Design a comprehensive survey ^{9,10} , with relevant questions tailored to the specific focus areas of HIV, TB, malaria and/or COVID-19 that you want to monitor. Include questions that capture essential information related to the identified indicators.
5. Choose the data collection platform	Select an appropriate online survey tool or platform based on your community's preferences and available resources.
6. Engage the community in data collection	Empower community members to actively participate in survey administration. Train and involve local community volunteers and peer workers to conduct the surveys and gather information from their peers.

⁹For example, see Ritshidze. Sex Worker Survey. Available at:

<https://ritshidze.org.za/wp-content/uploads/2023/06/Ritshidze-Sex-Worker-Survey-July-2023.pdf>

¹⁰For another survey example, see Stop TB Partnership. TB Stigma Assessment. Available at:

<https://www.stoptb.org/file/9474/download>

7. Distribute the survey online	Share the survey link through various channels, such as community meetings, health centers, social media, or emails. Ensure the survey reaches a diverse group of participants within the community.
8. Analyze and interpret the data	Once survey responses are collected, analyze the data to gain insights into the status of HIV, TB, malaria and COVID-19 within your community. Look for trends, patterns, and areas that require attention or improvement ¹¹ .

Tips

- Your survey should be logically constructed, and participants should feel the flow of your survey. In order to ensure a high response rate, put the least sensitive questions at the beginning and the most sensitive in the middle or close to the end of the survey.
- Try to use validated tools and questionnaires. The surveys and screening questionnaires have been tested to produce reliable, accurate results. Thus, you will avoid the complicated survey validation process among your potential participants. (For example, you would like to measure discrimination in healthcare. To use validated tools, you can find them on the websites of international organizations such as WHO or UNAIDS¹² or national health authorities such as ECDC¹³, CDC, or EMCDDA).

¹¹ ATAC is developing resources on data analysis and communications, partnerships, and advocacy to further support CLM implementers, which can be useful to turn to regarding the next steps of working with the collected data.

¹² UNAIDS. 2022. Global AIDS Monitoring 2023. Available at: https://www.unaids.org/sites/default/files/media_asset/global-aids-monitoring_en.pdf

¹³ ECDC. 2022. Stigma: Survey of People Living with HIV. Available at: <https://www.ecdc.europa.eu/sites/default/files/documents/hiv-stigma-survey-monitoring-dublin-declaration.pdf>

- After you create a survey, you need to find the best way to publish and distribute it, such as a website link. In order for the participants to gain access to the survey and for data to be collected, the link needs to reach the participants. This can be done differently, depending on the particular area/focus of the survey/type of data being collected and on how narrow or wide the participants group is. If you are targeting a small group of people, you can send the link to them directly and ask them to fill it out or meet with them virtually and read out the questions to them and provide responses to the survey based on their answers. If you are aiming at a broader group – wanting to reach many members of a given community, for example – you can distribute the link via email, text messages, social media messages, or groups/pages, etc., where you know the community is present.

Tools and Platforms

There are many online platforms and tools that you can use to support you in your CLM efforts. When choosing a platform to create your survey on, pay attention to data safety and security and cost considerations to ensure the safety of your participants and the efficiency of your CLM efforts.

Tool	Website	Free/Paid	Description / additional features
Microsoft Forms	https://www.microsoft.com/en-gb/microsoft-365/online-surveys-polls-quizzes	Paid (after 1-month free trial)	An online survey creator integrated into Microsoft Office 365. Some features are available only for the paid plans, Business or Education.
Google Forms	https://www.google.com/forms/about/	Free	A free online survey administrator included as part of Google Editor.
Jotform	https://www.jotform.com	Paid	A form builder used to collect various types of data, including voice recordings and geolocations.
Alchemer (formerly SurveyGizmo)	https://www.alchemer.com	Paid	An online survey software tool for designing forms, collecting data, and performing analysis.
Kobo Toolbox	https://www.kobotoolbox.org	Free	A free and open-source tool that is generally used for mobile data gathering.
Qualtrics	https://www.qualtrics.com	Paid	Often used as a survey tool, combined with SPSS/R/Stata to analyse the collected data.
SoGoSurvey	https://www.sogosurvey.com	Free/Paid	An end-to-end survey design, distribution, and analysis platform.
SurveyMonkey	https://www.surveymonkey.com	Free/Paid	Allows you to design and host your survey.
SoSci Survey	https://www.soscisurvey.de	Free/Paid	Exchange of questions between different survey projects. Sending individualized SMS directly from SoSci Survey.

When using open-source, free, and commonly used software, it is important to pay additional attention to issues of data security and privacy and make sure access to the data is limited to the CLM implementers carrying out the survey.

More information on some of these tools can be found in ITPC’s **“A Guide to Data Analysis Methods in Community-Led Monitoring”**¹⁴. Another resource that provides a practical, ready-to-use, step-by-step recipe of key CLM tools is the **“Practical handbook on community-led-monitoring tools”**¹⁵ by EHRA, which can be used in connection with another web tool¹⁶ designed specifically for choosing CLM tools that best match your needs.

Online focus group discussions

Online focus group discussions provide a valuable way to collect data from multiple participants simultaneously. This can be used when the topic is not too sensitive or personal, and relevant peers (e.g., a group of community representatives who receive a particular service at a particular site) can be brought together and asked the same questions. For example, questions suitable for focus groups relate to participants’ opinions about the quality of the service and areas for improvement. On the other hand, questions on a more sensitive topic, for example, questions about personal experience of stigma and discrimination from services because of an individual’s drug use/HIV status, might be more suitable for surveys. Focus group discussions offer insights into group dynamics and interactions; non-verbal cues can provide additional cues that are not verbally expressed by the participants but can be useful for interpreting the data, thus enhancing data analysis. These focus groups involve guided but open discussions on specific topics, with the moderator setting ground rules and facilitating respectful exchanges.

¹⁴ ITPC. 2023. A Guide to Data Analysis Methods in Community-Led Monitoring. Available at: https://itpcglobal.org/wp-content/uploads/2023/03/0228_CLM_DataManagementTools-2.pdf

¹⁵ EHRA. 2022. Practical handbook on community-led monitoring tools. Available at: <https://harmreductioneurasia.org/news/practical-handbook-on-clm>

¹⁶ EHRA. CLM Tool. Available at: <https://harmreductioneurasia.org/clm-tool>

Pros of Online Focus Groups	Cons of Online Focus Groups
Convenience: Participants can join from anywhere with internet access, reducing geographical constraints.	Technical Issues: Participants may face technical issues like poor internet connection, affecting communication.
Cost-Effective: Eliminates the need for travel, venue, and refreshments, making it more budget-friendly.	Limited Non-Verbal Cues: Online settings may limit non-verbal communication cues compared to in-person interactions.
Anonymity: Participants can feel more comfortable expressing opinions due to the virtual environment.	Difficulty in Building Rapport: Building rapport among participants can be more challenging in a virtual setting.
Time Efficiency: Scheduling and conducting online focus groups can be more time-efficient.	Access Barriers: Some individuals may not have access to a computer or stable internet, limiting participation.
Recordability: Easier to record and analyze discussions with online tools.	Loss of Personal Connection: Participants might feel less connected compared to face-to-face interactions.
Diverse Participant Pool: Easier to include a diverse range of participants from various locations.	Distractions: Participants may face distractions at home or in their environment.
Transcription Ease: Digital discussions can be transcribed more efficiently for analysis.	Security Concerns: Online platforms may pose security risks, especially when discussing sensitive topics.
Global Reach: Enables the inclusion of participants from different time zones or countries.	Technology Literacy: Some participants may not be familiar with the technology.
Flexibility: It is easier to accommodate diverse schedules and time zones.	Flexibility: It is easier to accommodate diverse schedules and time zones.

Online focus group discussions, conducted in real-time through virtual platforms, closely resemble face-to-face interactions. While technology issues may be a concern, advancements in reliable technology have minimized such problems. When moving focus group discussions online, it is essential to consider unique aspects:

1. Sample Size: Due to potential technology challenges, it is recommended to have smaller groups of around 6 participants.

2. Group Dynamics: Establish ground rules to encourage respectful interactions, such as using text chat or virtual hand-raising functions to avoid interruptions.

3. Tools: Choose familiar video-conferencing platforms like **Microsoft Teams, Zoom, Webex, or GoToMeeting**,¹⁷ allowing for easy data recording and transcription, as well as easy access for the participants. Provide additional instructions and support for the participants to make sure they do not avoid participation due to the tool being unfamiliar to them. Video-conferencing platforms have safety and security concerns, including the risk of unauthorized access and data breaches. To minimize these risks, make sure that meetings are password-protected, use waiting rooms to control participant access, and regularly update your computer software. Also, educate participants about the importance of not sharing meeting links publicly and enabling multi-factor authentication.

To encourage participation, moderators can utilize user-friendly response modalities like Padlet, Etherpad, or WordCloud, enabling alternative and anonymous contributions from all participants simultaneously. By following these considerations, CLM implementers can effectively conduct online focus groups and gather valuable insights from their communities.

¹⁷ These video-conferencing platforms are also great tools for conducting online interviews. You can find more information about these platforms in the following section about remote interviews.

The table below is an example of a focus group discussion guide (the excerpt is from FHI360’s resource).¹⁸ Other helpful examples can be found in EHRA’s resource about CLM monitoring.¹⁹

Discussion Questions		Score (0-4)	Reason for Score	Suggestion for Improvement
B	Quality of Health Center Services			
1	How beneficial is pre- and post-test counseling for HIV testing?			
2	How is the quality of HIV service provision?			
3	How is the quality of STI services (counseling and management or signs and symptoms)?			
4	How is the quality of violence response services?			
5	How is the quality of HIV treatment initiation counseling?			
6	How is the quality of antiretroviral therapy (ART) adherence counseling by health facility/site providers?			
7	How is the quality of ART support for adherence by peer navigators?			
8	How effective are providers at communicating options for how/where you can pick up ART (multi-month dispensing [MMD], community ART options, pharmacy pickup, etc.)			
9	How is the quality of viral load testing?			

¹⁸ FHI360. 2021. Community-Led Monitoring Technical Guide. Available at: <https://www.fhi360.org/sites/default/files/media/documents/resource-epic-community-led-monitoring-technical-guide.pdf>

¹⁹ EHRA. 2022. Practical handbook on community-led monitoring tools. Available at: <https://harmreductioneurasia.org/news/practical-handbook-on-clm>

Discussion Questions		Score (0-4)	Reason for Score	Suggestion for Improvement
A	Access to Services			
1	How convenient are times of site/facility hours?			
2	How convenient are times of mobile services?			
3	How convenient is the location of the site/facility?			
4	How convenient are locations of mobile services if offered by the site/facility?			
5	How easily can you access HIV services (pre-exposure prophylaxis [PrEP], HIV testing, HIV treatment, viral load testing)?			
6	How easily can you access prevention commodities such as condoms and lubricant?			
7	How easily can you access sexually transmitted infection (STI) services?			
8	How easily can you access violence response services (such as post-exposure prophylaxis, crisis response teams, or a trained counselor)?			
9	How effectively are you navigated/linked to the site/facility when reached in the community?			

Remote Interviews

Remote interviews are another valuable method for CLM that offers flexibility and convenience for participants. Both one-to-one and group interviews can be done remotely. Depending on the needs, sample sizes can vary, but **smaller groups** are recommended for remote interviews to address potential technology challenges. Remote interviews can include key informant interviews with service providers.

A group interview and a focus group discussion share the commonality of involving a group of participants, but they differ in several aspects. Focus groups are deliberately designed to foster interaction among participants, encouraging discussion and debate around a specific topic. Focus group discussions often involve a more open-ended and flexible approach. In contrast, in group interviews, the focus is on participants' individual responses and interaction between the interviewer and participants. Group interviews are often used as a quicker and more cost-effective way to gather data from several participants compared to one-to-one interviews, but if the topic is very sensitive and personal, one-to-one interviews might be a better option.

To conduct successful interviews, preparation is key. Designing an interview guide* with open and engaging questions helps build trust and rapport with participants. Consider the sequence of questions, grouping them into topics and ensuring logical flow to encourage elaboration.

Remote interviews can be conducted via telephone, email, or video-conferencing platforms. Each method has its advantages and disadvantages. For telephone interviews, recording the conversation is helpful for later reference, and a positive script for the introduction is recommended.

Email and **online interviews** offer convenience for participants, especially when addressing sensitive topics, but require access to computers and literacy skills. Video-conferencing interviews allow face-to-face interactions, maintaining a meaningful connection with participants. Familiarize yourself with the technology and choose a location with privacy for video-conferencing interviews.

Email interviews have a lot of similarities with surveys in terms of that you send the questions to the interviewee and they respond via email. The difference is that in email interviewing, you can respond to the interviewee's answers with follow-up questions, which allows for a more dynamic and in-depth exploration of their responses.

*** See Appendix 1 and 2 for examples of interview guides**

Email and online interviews

Advantages and Disadvantages

Participants

Pros	Cons
One of the main advantages of email and online interviews is the convenience for participants. Persons can participate at a time and place that is convenient to them and take as long as they need to think about their answers. This lends a greater sense of control, which adds the factor of empowerment to the process.	Email and online interviews limit participation to those with access to computers and mobile phones and those with a certain level of literacy skills.
Anonymity in online or email interviews and perceiving less social pressure and visual clues from the interviewer might make participants more comfortable in sharing sensitive and personal information. This is of particular value when exploring sensitive topics.	Participants may find typing rather than speaking inconvenient.

CLM implementers/interviewers

Pros	Cons
Advantages for the CLM implementers lie in the need for fewer resources, as there is no need for transcription, no loss of raw data, and no costs for travel to interview locations. Therefore, larger sample sizes may be possible than in the case of face-to-face interviews.	The CLM implementers' main disadvantages include having less control over the interviews and the potential loss of spontaneity, natural responses, and non-verbal cues from their participants.

There is also a potential for engaging more with the data during collection, as the extended timeframe offers **member checking**²⁰ (**participant validation opportunities**) and for the formulation of prompts and follow-up questions tailored to the participants developing account.

Interviews via video-conferencing and mobile platforms

When compared, face-to-face and online video-conferencing interviews do not reveal any difference in the quality of the interviews. Many advantages and disadvantages are similar to those discussed in email and online interviews.

Many readily available video-conferencing platforms like **Microsoft Teams, Zoom, Webex, BlueJeans, Skype, and GoToMeeting** can be used to successfully carry out an online interview. Many of these platforms allow you to record sessions and easily transcribe the collected data. Mobile platforms such as Facebook Messenger, WhatsApp, and Signal are also used for video interviews in many countries because they are more accessible.

Tool	Website	Free/Paid	Description / additional features
Microsoft Forms	https://www.microsoft.com/en-gb/microsoft-teams/group-chat-software	Free/Paid	A user-friendly video-conferencing platform integrated into Microsoft Office 365. Some features are available only for the paid plans.
Zoom	https://zoom.us/	Free/Paid	A communications platform that allows users to connect with video, audio, phone, and chat. Some features are available only for the paid plans.
Webex	https://www.webex.com/	Free/Paid	A cloud-based video-conferencing platform. Some features are available only for the paid plans.
BlueJeans	https://www.bluejeans.com/	Free	A cloud-based video-conferencing platform for online meetings and webinars.
Skype	https://www.skype.com/en/	Free/Paid	A platform where people can have free video and voice one-to-one and group calls and send instant messages. There is also a paid version where you can call phones and send SMS.

²⁰ Member checking (also referred to as participant validation) is a technique where data are returned to participants to check for accuracy and resonance with their experiences.

GoToMeeting	https://www.goto.com/meeting	Paid (after 14 days of free trial)	An online meeting, desktop sharing, and video conferencing software by GoTo.
Facebook Messenger	https://www.messenger.com/	Free	Instant messaging and audio/video calling app developed by Meta Platforms.
WhatsApp	https://www.whatsapp.com/	Free	Instant messaging and audio/video calling app owned by Meta Platforms.
Signal	https://signal.org/	Free	Instant messaging and audio/video calling app focused on privacy.

Advantages and Disadvantages

Participants

Pros	Cons
Video-conferencing interviews can be done without compromising a meaningful connection with the interviewees.	Populations with limited internet access are disadvantaged in participating in interviews via video-conferencing platforms.
The most significant advantage of interviews via video-conferencing platforms is accessibility to participants, their convenience, and health safety.	Participants may have distractions or a lack of privacy while participating in the interview.
Some participants express feeling more comfortable speaking about sensitive topics in their own space rather than in an unfamiliar environment.	

CLM implementers/interviewers

Pros	Cons
Video conferencing allows the CLM interviewers to observe the interviewees' non-verbal communication and provides a glimpse into the participant's life.	Extra costs (hardware, software, fees, etc.).
Over the past two years, many people have become familiar with video-conferencing platforms. With the increased familiarity with social media, reluctance to participate in an online interview is no longer a disadvantage.	Possible technical difficulties setting up or conducting the interviews and uploading the recordings. Even though the interviewer and interviewee can hear and see each other, they do not occupy the same physical space, making responding to emotional cues and body language more difficult.

To ensure successful video-conferencing interviews, test the platform beforehand, provide technical information to participants, and plan for potential distractions. Prioritize video-conferencing platforms that you and your team are comfortable with, and consider using AI transcription software for efficient data processing.

Here is an example of an online interview guide (excerpt)

1. What is your position/role at or in relation to [NAME OF SITE/HEALTH FACILITY] health facility or site?
2. How long have you worked with/at [NAME OF SITE/HEALTH FACILITY] health facility or site?
3. Which of the following populations receives services at this health facility/site? [Add choices based on your project's target group if needed]
 - a. Female sex workers (FSWs)
 - b. Men who have sex with men (MSM)
 - c. Transgender people (transgender)
 - d. People who inject drugs (PWID)
 - e. Adolescent girls and young women (AGYW)
 - f. People living with HIV (PLHIV)
4. What challenges does this site face in providing services to:
[Select only the relevant population(s) based on the answer to Question 3.]
[FSW/MSM/Transgender/PWID/AGYW/PLHIV?]
5. Has your facility/site experienced stock-outs of any of the following:
 - a. HIV test kits
 - b. Condoms/lubricant
 - c. ART
 - d. STI drugs
 - 5a. If yes, how often do stock-outs of HIV test kits occur?
 - 5b. If yes, how often do stock-outs of condoms/lubricant occur?
 - 5c. If yes, how often do stock-outs of ART occur?
 - 5d. If yes, how often do stock-outs of STI drugs occur?
6. Is your health facility/site successfully encouraging [Select only the relevant population(s) based on the answer to Question 3]
[FSW/MSM/Transgender/PWID/AGYW] to get tested for HIV?
 - a. If yes, please describe what makes the facility/site successful.
 - b. If no, please describe why the facility/site is not successful.
7. What one change would improve HIV testing uptake among [Select only the relevant population(s) based on the answer to Question 3]
[FSW/MSM/Transgender/PWID/AGYW]? Why?

For the full example of the interview guide, please see the **Community-Led Monitoring Technical Guide**²¹ by FHI360.

Regular/ongoing/routine CLM data collection using digital platforms

Another method for CLM that is gaining popularity and is being more and more widely used by communities around the world is utilizing existing or developing specific digital platforms for ongoing, regular monitoring of service provision by communities.

Examples of such programs include:

- **OneImpact**²²

The OneImpact platform consists of 3 parts:

1) TB Affected People App – 4 modules that provide information on TB, TB services, a way to connect with others from the TB community and to report any barriers that they face in accessing care or treatment.

2) First responder dashboard – a platform to allow first responders to monitor barriers reported by people affected by TB and to prompt the coordination of a response.

3) Accountability dashboard – a platform for the community and other TB stakeholders to monitor CBM indicators that will inform the design of programmatic interventions and facilitate the evaluation of interventions that address the barriers to access, enhancing accountability in the TB response.

OneImpact is a free tool that is secure, encrypted and easily accessible. It can be used for CLM focused on TB-related topics, for example, human rights violations, TB stigma, barriers to TB health services, and barriers to TB support services. If your CLM does not relate to TB, other online platforms might be a better choice.

²¹ FHI360. 2021. Community-Led Monitoring Technical Guide. Available at: <https://www.fhi360.org/sites/default/files/media/documents/resource-epic-community-led-monitoring-technical-guide.pdf>

²² OneImpact. Available at: <https://stoptbpartnershiponeimpact.org/>

- **REAct**²³

This free digital tool allows communities to document human rights violations, identify barriers and gaps, and come up with solutions to protect their rights and freedoms.

Currently, it functions in 13 countries of the EECA region, is operated by 363 REActors, and has 13,179 registered cases. Globally, REAct has been used by 272 organisations in 36 countries in Africa, the Middle East, Central Asia, and Eastern Europe.

The database can be adapted to allow for collecting other types of data and tracking other aspects of service provision/epidemic response.

If your CLM focuses on human rights violations, stigma, and discrimination, **REAct is a suitable tool**, but it requires trained staff (REActors) to use it effectively. REAct was originally developed to focus on HIV, but it can be adapted to TB, hepatitis C, sexual and reproductive health (SRH) services, harm reduction interventions for people who use drugs, and others.

- **DHIS2**²⁴ / **CHIS**²⁵

DHIS2 is a global open-source project coordinated by the HISP Centre at the University of Oslo (UiO). More than 80 countries worldwide use DHIS2 to collect and analyze health data. DHIS2 is offered free of charge as a global public good. DHIS2 is usually used at the government and facility level.

The Community Health Information Systems (CHIS) DHIS2-based metadata package is designed to facilitate the capture and analysis of a core set of indicators for community-based health services and can be used for CLM.

²³ REAct. Available at: <https://react-aph.org/en/>

²⁴ DHIS2. Available at: <https://dhis2.org/>

²⁵ CHIS. Available at: <https://docs.dhis2.org/zh/topics/metadata/chis-community-health-information-system/design/chis-general-design.html>

- **CommCare**²⁶

Used in over 50 countries, CommCare is the most widely adopted, technically advanced, and evidence-based mobile platform for low-resource settings. Some of these may not all be specifically designed as CLM tools, but the data they allow to be collected routinely and on a regular basis can be analysed as a part of the CLM efforts. CommCare offers great customization options, good security, and offline access. CommCare for organisational use costs USD 250–1000 per month, which may be a prohibitive expense for small organisations.

These are oftentimes focused on one particular area and can be used to monitor one aspect of what is needed and not cover all CLM needs. Thus, a community organization needs to complement the usage of these programs with additional CLM efforts, e.g., the ones described in the previous sections of this guide or a combination of several digital platforms.

Additionally, there are comprehensive CLM implementation systems that can be adapted for and adopted by communities from countries that have not introduced them yet that help communities focus and sustain their CLM efforts in a structured and defined manner (**e.g., ITPC’s Community Treatment Observatory (CTO) Model**²⁷ **and Ritshidze Program**²⁸).

Communities’ technical partners around the world are continuing to develop new technological solutions to help them collect data regularly and on an ongoing basis, so it is important to stay up to date on what is available and be open to the possibility of exploring and using new approaches to improve your CLM programs and – **as a result – availability, accessibility, acceptability, and quality (AAAQ) of health services you receive.**

If your CLM program has sufficient resources, such digital solutions can be very useful. However, for start-up CLMs, this may not be a viable option. In such cases, a start-up CLM program can use the data gathered from these digital platforms by other people, which can then be considered as a review of secondary data sources. This topic is discussed in the next section.

²⁶ CommCare. Available at: <https://www.commcarehq.org>

²⁷ ITPC. 2019. The Community Treatment Observatory (CTO) Model Explained. Available at: <https://itpcglobal.org/wp-content/uploads/2019/02/ITPC-CTO-Model-Full-Eng.pdf>

²⁸ Ritshidze Program. Available at: <https://ritshidze.org.za/>

Records/archives/health registry reviews

Records/archives/health registry reviews (also known as secondary data) in community-led monitoring (CLM) refer to information that is collected by others for their own purposes but can be valuable for CLM efforts. For example, if you are **challenging CLM data to data from other sources**, you need to have access to the latter so that you can use it for your analysis and further communication. For example, if your CLM initiative aims to assess the accuracy of reported HIV testing rates within a community, you can challenge your collected data by comparing it with the official HIV testing records maintained by local health authorities.

Access to these health registry reviews allows you to cross-verify the reported testing numbers, ensuring the reliability of your CLM findings. Apart from challenging CLM data, secondary data is also used to reinforce and/or triangulate CLM data from different sources. This data can be both quantitative and qualitative.

You can request information from various institutions, like statistics or monitoring results, to support your CLM needs, or you can use existing previously published reports or other documentation, interview scripts or audio recordings from interviews or focus groups, visual materials – photos, surveillance reports, etc.

When using quantitative secondary data, it is crucial to understand the data collection process, response categories, and other relevant details on the process that was organized and carried out by others. Some sources for secondary data include international organizations, governmental institutions, research institutions, and open-access databases.

The **advantages** of using secondary data include saving time and costs, as someone else has already collected the needed information. However, it is essential to be cautious and ensure the data meets the specific needs of your CLM activity. Verify the reliability and credibility of the data, especially for quantitative sources, and be aware of any limitations or missing information.

While using secondary data in CLM has its benefits, there are some downsides to keep in mind. One main issue is that you have less control over how the data was collected. Because you did not collect it yourself, you cannot decide on things like survey questions or how the data was gathered. This might make the data less relevant to what you specifically need for CLM.

Another concern is about the quality of the data. Secondary data can vary in how reliable, accurate, and complete it is. Other challenges include ethical and legal issues, the risk of relying too much on existing information, and the possibility of misunderstanding the data because you might not know the context in which it was collected. Even though using secondary data can save time and money, it is important to make sure it really fits the goals of your CLM project.

Remember, secondary data can be a valuable resource for CLM, but careful evaluation and understanding are essential to ensure its suitability for your specific needs.

Other CLM data collection tools and methods

Social Harm Reporting Forms

- individual reports of adverse events and incidents of harm that are filled out and collected from recipients of care accessing health services

Appendix 1: Toll-free Helpline Social Harms Reporting Form

District: _____



Date of contact with client	Client name (first name only)	Details of incidents reported (provide detailed description for each incident; use more sheets as needed)	Referral		Client is willing to discuss GBV/ social harms with study team (Y/N)	Client phone number (if willing to be contacted by study team)	Client ward/ community (if willing to be contacted by study team)	Helpline staff receiving the report (staff initials and date)	Client contacted by study team (staff initials/ date)
			Client referred to support organisation (Y/N)	Organisation(s) to which client referred					

Community Scorecards

- used by both community members (including civil society organizations and advocates) and healthcare providers to obtain community feedback on services and/or take a deeper dive into issues reported through individual recipient of care feedback;
- community scorecards can also be used in online surveys.

Here is an example of how a community scorecard can look like (excerpt)

Scoring Definitions

Not Applicable	Needs urgent remediation				Needs improvement				Meets expectations		Surpasses expectations
N/A	0 No/ Never/ Does Not Exist	1 Very poor	2 Poor	3 Well below average 	4 Below average	5 Average/ Sometimes	6 Above average	7 Well above average 	8 Good	9 Very good	10 Yes/ Always/ Excellent

Performance Indicator Discussion Questions		Score (0-10)	Reasons/ Comments
1	Quality of Health Center Services		
1.1	How easily can KPs access HIV testing and counselling services?		
1.2	How beneficial was pre- and post-test counselling for KPs?		
1.3	How effectively were KPs counselled on sexually transmitted infections (STIs) management or signs and symptoms?		
1.4	How effective was HIV & AIDS treatment initiation counselling?		
1.5	How effective are facility HIV		

For a full example of a scorecard and tips on its adaptation, please see the **Community Scorecard Toolkit**.²⁹

Online data collection methods are versatile and adaptable. They offer a flexible approach and gather information through various tools such as surveys, interviews, and focus groups. This versatility allows for a mix of quantitative and qualitative approaches and provides a comprehensive understanding of community perspectives and experiences. Online CLM data collection methods allow participants to engage from different locations, which fosters inclusivity and ensures a broader representation.

Final Tips

Clearly communicate the purpose and benefits of online data collection to participants and make sure they understand how their input contributes to the broader CLM efforts. Tailor your online methods to the specific needs and characteristics of the community, taking into account cultural differences, IT literacy levels, and technological accessibility to encourage maximum participation.

Prioritize data security and privacy. Implement measures to protect participant information and adhere to ethical standards, particularly when addressing sensitive topics. Provide training and support for participants who may be unfamiliar with online tools so that they feel comfortable and confident in contributing to the CLM process. Diversify your data sources by combining online methods with other approaches, such as in-person interviews, to create a more comprehensive understanding of the community context.

Establish a regular feedback loop with participants and keep them informed about the progress and outcomes of the CLM initiative. This fosters a sense of ownership and community engagement and reinforces the collaborative nature of the monitoring process.

You should also remain adaptable and ready to adjust your online data collection strategies based on ongoing feedback and changing community dynamics. Flexibility is key to ensuring the success and relevance of your CLM implementation.

²⁹ Advancing Partners & Communities. 2018. Community Scorecard Toolkit. Available at: https://www.advancingpartners.org/sites/default/files/sites/default/files/resources/tagged_apc_lci_community_scorecard_toolkit.pdf

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Annexes

Annex 1

1. CBM Programme Indicators (sample)

Availability

- % of people affected by TB for whom TB treatment care and support services are unavailable
- % of people who never got tested and never got a TB test result
- % of people diagnosed with TB who reported not starting treatment
- % of people diagnosed with TB who cannot access TB treatment

Access

- % of people with TB who experience human rights barriers that prevent access to services in the TB response
- % of people with TB who cannot access TB services because of financial barriers
- % of people with TB who cannot access TB services because of geographical barriers

Acceptability

- % of people with TB who find TB treatment care and support services unacceptable
- % of people with TB who experience stigma in health care settings
- % of people with TB who experience stigma in community settings
- % of people with TB who experience stigma in family settings
- % of people with TB who experience self-stigma
- % of people with TB who experience discrimination due to TB
- % of people whose right to confidentiality was violated.

Quality

- % of people with TB who find the quality of TB treatment care and support services poor
- % of people with TB who found TB health facilities unhygienic
- % of people with TB who had to wait too long for TB services
- % of people with TB who cannot manage TB drug side effects

2. CBM Programme Indicators (sample)

- No. of App users
- % of Active users % of Repeat users
- Usage quality

3. CBM Indicators (Efficiencies of the First Responders)

- Resolution status-issue type wise
- Resolution efficiency- issue type wise

Annex 2

1. CBM Programme Indicators (sample)

Availability

- % of people affected by TB for whom of TB treatment care and support services are unavailable
- % of people who never got tested and never got a TB test result
- % of people diagnosed with TB who reported not starting treatment
- % of people diagnosed with TB who cannot access TB treatment

Access

- % of people with TB who experience human rights barriers that prevent access to services in the TB response
- % of people with TB who cannot access TB services because of financial barriers
- % of people with TB who cannot access TB services because of geographical barriers

Acceptability

- % of people with malaria who find malaria treatment care and support services unacceptable
- % of people with malaria who experience stigma in health care settings
- % of people with malaria who experience stigma in community settings

- % of people with malaria who experience stigma in family settings
- % of people with malaria who experience self-stigma
- % of people with malaria who experience discrimination due to malaria
- % of people whose right to confidentiality was violated

Quality

- % of people with malaria who find the quality of malaria treatment care and support services poor
- % of people with malaria who found malaria health facilities unhygienic
- % of people with malaria who had to wait too long for malaria services
- % of people with malaria who cannot manage malaria drug side effects

2. CBM Indicators (APP Usability)

- No. of App users
- % of Active users
- % of Repeat users
- Usage quality

3. CBM Indicators (Efficiencies of the First Responders)

- Resolution status-issue type-wise
- Resolution efficiency- issue type-wise

Annex 3

A sample informed consent form for participants in CLM

INFORMED CONSENT FORM TO BE SIGNED BY ALL PARTICIPANTS

Hi. My name is **[DATA COLLECTOR'S NAME]**. I am part of a team that is implementing community-led monitoring interventions in **[LOCATION]**. I am going to start by explaining this project and making sure you are comfortable participating. Is it all right if I continue?

DESCRIPTION OF THE PROJECT

- You are invited to participate in CLM implementation.
- CLM is a mechanism that systematically and routinely collects and analyses information from health facilities and the people who access services there.
- The purpose of the project is to analyse this information to identify gaps in access to and quality of services and care and to inform advocacy for improving them.
- You have been asked to participate because you have accessed services at **[FACILITY NAME]**.
- This study will include a sample of about [number] participants from **[NUMBER]** health facilities.

WHAT WILL YOUR PARTICIPATION INVOLVE?

- If you decide to participate in this project, you will be asked to answer **[NUMBER]** questions. This part will take about **[ESTIMATED LENGTH]** minutes.
- You might also be asked to participate in a group discussion, where you will be asked to share more about your experience accessing services at this health facility. This part will take about [estimated length] minutes.
- You are free to ask any questions that you have before, during and after the interview.

ARE THERE ANY RISKS TO ME?

- This project is anonymous. Neither your name nor any other identifying information will be recorded in the questionnaire or in the final report.
- Due to the nature of HIV and sexual and reproductive health, several questions are personal in nature and others include topics like sex and stigma and discrimination.
- If at any time you are uncomfortable with the content of the discussion, you may choose to skip a question or stop participating completely. Completion of all the questions is voluntary and you may stop or withdraw at any time.

ARE THERE ANY BENEFITS TO ME?

- After completion of these questions, you will be given information about HIV and sexual and reproductive health and rights. This may benefit your own awareness and access to services.
- You will be given a transport allowance of **[AMOUNT]** for your participation in this project.
- Your participation will help improve access and quality to HIV prevention, services and treatment in **[COUNTRY NAME]**.

Please feel free to contact the community treatment observatory team leaders. If you have any questions about this process, the contact details of the team leader are:

- **[NAME] [PHONE NUMBER]**
- **[NAME] [PHONE NUMBER]**

STATEMENT OF CONSENT: I have read/heard and understood the above information and I have had all my questions answered by the interviewer. I agree to participate in the process voluntarily.

NAME OF THE PARTICIPANT

SIGNATURE OF THE PARTICIPANT

NAME OF THE INTERVIEWER

SIGNATURE OF THE INTERVIEWER

DATE OF THE INTERVIEW: _____

Annex 4

“The Five As” - A Person-Centered Conceptual Framework for Access

Availability	Accessibility	Acceptability	Affordability	Appropriateness
<ul style="list-style-type: none"> Do the required health services, medicines, commodities and supplies exist? If so, do they exist when they are needed and in adequate supply? 	<ul style="list-style-type: none"> Are there long travel distances or wait times? Are the hours of operation convenient? Are referral processes along the care cascade smooth? 	<ul style="list-style-type: none"> Is there a high quality of care? Are services provided free of stigma and discrimination? Are the human rights of patients promoted and protected? 	<ul style="list-style-type: none"> Do services require out-of-pocket spending on behalf of the client? Is the service delivery model(s) efficient? What is the sustainability of response? 	<ul style="list-style-type: none"> Are services tailored to the specific needs of key and vulnerable populations? Are age and gender considered in service packages?

